

STATEMENT OF -----

-----, **MINNESOTA**
for

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE ALLOWANCE
INITIATIVE HEARING ON
YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA**

JULY 29, 2009

I am a professional who works with people with Alzheimer's disease. Over the past 12 years, I have had the great pleasure of knowing many people living with younger onset Alzheimer's and faced the great challenge of assisting them in living their best lives with the illness. Alzheimer's is a devastating disease, impacting every aspect of a person's life. Like a thief in the night, it slowly takes away memory, language, judgment, and all those things that make us uniquely who we are.

Very early on, Alzheimer's disease impairs an individual's ability to multi-task, pay attention, perform calculations, follow complex instructions or directions, and, for most people, these changes mean that they are no longer able to continue successfully in their jobs. Many people I have known have been fired, others have quit their jobs to avoid the embarrassment of being terminated, a few have been able to work with their companies with accommodations for a time, but all have eventually lost their jobs in the prime of their careers.

Most people don't think about having Alzheimer's disease in their 40s and 50s, and don't plan on being unable to work again for the rest of their lives. They are completely blindsided by this diagnosis, and faced with living the next 8 to 20 years with a terminal illness that gradually robs them of their independence. Many people have children at

home or in college, and for some, the person with younger onset Alzheimer's is the sole family bread-winner.

Once a diagnosis is made, a process which often takes more than a year, people with younger onset Alzheimer's are forced to apply for SSDI. Many are turned down two and three times before finally being accepted. Many are told that they are not sufficiently impaired yet to qualify, leaving them without any source of income. Because one must be on SSDI for two years before qualifying for Medicare, people with younger onset Alzheimer's who have lost their jobs often also do not have medical insurance for years at a time when they need it most.

Imagine being diagnosed with Alzheimer's disease, a terminal illness, at age 45. You've got two kids at home and you are the sole breadwinner. You've had to quit your job because you could not "keep up". Your illness robs you of the ability to learn new things, so getting another job really isn't an option. Your career is over at midlife, and you know that your life will be cut short. You apply for SSDI, but you are declined. Your spouse goes back to work to support the family, but your disease makes it dangerous for you to be home alone all day. It's a risk you have to take. You could be on medications for the disease, but when you lost your job, you lost your health insurance and these drugs are expensive. You've gone from being at the top of your career to wondering if you will lose your house in a year.

This story is heartbreaking, and sadly all too familiar. As a professional working with these families, it's unthinkable to me how someone with a terminal illness that even early on impairs the ability to use language effectively, drive a car, learn new information, and multi-task and as the disease progresses robs the individual their

ability to communicate, walk, understand, recognize their friends and family, and remember who they are, could not qualify for SSDI. If people with younger onset Alzheimer's are not eligible for compassionate allowance SSDI, I can't imagine who would be.

On behalf of all of those people living with younger onset Alzheimer's, their friends and families, urge you to approve compassionate allowance today.